

January 2009

To: All State Bar Associations

**From: Sam Golden, Chair, VOR Government
Affairs Committee**

**RE: Communication with American Bar Association
regarding recent efforts to dilute the rights of
legal guardians of persons with profound
developmental disabilities.**

Enclosed please find VOR's recent correspondence to the American Bar Association's Commission on Law and Aging asking for its support regarding a situation of grave concern to legal guardians of individuals with profound developmental disabilities.

As is detailed in the attached correspondence, the rights of legal guardians of persons with profound developmental disabilities – usually close relatives – are being diluted by advocacy activities which seek to counter the residential choices we, as guardians, have made on behalf of our family members.

Specifically, some advocacy organizations, state officials and federal officials actively seek to close our relatives' specialized residential facilities, over our express objections. These activities are motivated by ideology and/or profit.

Legal guardianship, as you know, is governed by state law, with state-by-state variances. As such, we felt it was as important – if not more important – to raise our concerns with each State Bar Association.

If have any questions or feel your Bar Association can be of some support to legal guardians in your state, please contact Tamie Hopp, Director of VOR Government Relations and Advocacy at 605-399-1624 or Tamie327@hotmail.com.

January 13, 2009

Joe O'Connor, J.D., Chair
Charles P. Sabatino, Director
American Bar Association
ABA Commission on Law and Aging
740 15th Street, N.W.
Washington, D.C. 20005-1022

By Facsimile: (202) 662-8698

By E-mail: Sabatinoc@staff.abanet.org

**RE: RECENT EFFORTS TO DILUTE THE
RIGHTS OF LEGAL GUARDIANS OF
PERSONS WITH PROFOUND
DEVELOPMENTAL DISABILITIES.**

Dear Chairmen O'Connor and Mr. Sabatino,

I represent VOR, a national advocacy organization representing people with developmental disabilities, and their families.

Nearly all of our members have family members with severe and profound mental retardation and related developmental disabilities. Our loved ones need substantial support in every aspect of life including walking, communicating, bathing, eating and toileting. They function at an infant or toddler's level although fully grown; they also endure multiple disabilities, chronic medical conditions and/or behavioral challenges. Many also have seizure disorders, mental illness, visual or hearing impairments, or have a combination of these conditions.

In most cases, our loved ones and their peers have been adjudicated incompetent and a legal guardian has been appointed for them, usually a parent or close relative.

We have a serious concern which falls within the Commission's work on legal issues relating to "capacity, guardianship and surrogate decision-making," as well as within "disability and individual rights." As legal guardians for our adult family members with severe cognitive disabilities, we are facing unprecedented attacks on our legally appointed rights and responsibilities as legal guardians. Like never before, some advocacy organizations for persons with disabilities, some state officials, and even some federal entities, have infringed upon our ability to carry out our duties as guardians, or have otherwise worked to undermine our status as

guardians. For example,

Illinois: In a December 2, 2008 letter to families, Lilia Teninty, Director of the Illinois Department of Human Services, writes: "I welcome the opportunity to address your question, 'Does the Illinois DHS now ask an individual who has a legal guardian about his or her placement preference without the guardian being present?', and my reference to the Nebraska Plan. As previously identified, we have a responsibility to recognize individual rights in exercising his or her personal choices and preferences, and with respect to this right, ***we believe that guardian permission is not required to discuss placement options.***" (*Emphasis added*).

Nebraska: The referenced Nebraska plan is a July 2008 Settlement Agreement between the State of Nebraska and the U.S. Department of Justice. Instead of encouraging informed choice with regard to residential placement decisions, this federal settlement agreement instead suggests additional "education" in situations where legal guardians disagree with community placement: "Where family members and/or guardians have reservations about community placement, the State shall provide ongoing educational opportunities to such family members and/or guardians with regard to placement and programming alternatives and options."

In **New Jersey, Georgia, and Florida**, and other states, advocates, some of whom are federally-funded, also visit ICFs/MR residents to discuss placement options, without legal guardian permission. This sort of communication with our profoundly developmentally disabled family members/wards is no different, and no less offensive, than if state and federal advocates entered schools to talk to children, one-on-one, without their parents' consent.

Illinois: The federally-funded Illinois Council on DD published a "Blueprint for System Redesign in Illinois," calling for the movement of people from ICF/MR settings over the objections and concerns of legal guardians, stating, "[t]heir objections should not circumvent the process."

California: In 2002, the federally funded California Protection and Advocacy agency (PAI) filed its second lawsuit to close ICFs/MR, arguing in court against family/guardian intervention, stating, "As a matter of substantive law, parents and guardians of institutionalized persons have different and potentially conflicting interests on matters pertaining to their child's or ward's constitutional or statutory rights to liberty and due process." PAI's first lawsuit was filed despite

overwhelming opposition by families and guardians. PAI's first lawsuit closed two ICFs/MR and transferred 2,500 people to alternate settings leading to reports of abuse, neglect and death.

Wisconsin: The Wisconsin P&A filed a lawsuit on behalf of *minor* residents of ICFs/MR, notifying their parents (legal guardians) after the lawsuit was filed in case they "might be interested."

Maine: A Maine P&A advocate counseled her mentally ill client, William, who was receiving inpatient psychiatric care, that his parents were a "negative force in his life" given their efforts to keep him "institutionalized" due to his severe mental illness. Her subsequent "victory" in winning his release was followed shortly by William murdering his mother.

Centers for Medicare and Medicaid Services (CMS): In 2007, CMS, an agency within the U.S. Department of Health and Human Services, published its official guidance to state governments for state Money Follows the Person programs. In this guide, CMS instructed *states (not courts)* to critique guardianship performance. VOR objected noting that the CMS MFP Instruction Guide,

"... directs states and CMS to critique and challenge the competency of each and every guardian, without regard to the existing judicial process in place, and without regard to statutory requirements relating to the role and responsibilities of guardians appointed by the individual's state court. It further encourages states to pursue the removal of guardians, who in their standards (as directed by CMS) don't measure up. Thus, CMS would usurp states' guardianship authority. This is an unacceptable interference with states' rights and would put every ward at risk of losing his or her appointed guardian."

Developmental Disabilities Assistance and Bill of Rights Act (DD Act) Programs: The three federally created and authorized DD Act programs routinely ignore and disrespect legal guardian involvement and choice. Several examples of P&A disrespecting family/legal guardianship involvement were noted above. It is not surprising, then, that the national association for state P&As, the National Disability Rights Network, signed a letter to Congress which called families, many of whom are legal guardians, as "clueless." In a related example, the National Association of State DD Councils proposed changes to the Act's "primary decisionmaking" clause which would cut out completely the current legal role of family members and legal guardians of adults with developmental disabilities.

Although characterized as an attack on our rights as legal guardians, the real victims of these undermining actions are our fragile family members with severe and profound developmental disabilities, who depend on our compassion and insights to make sound decisions in their best interests. As recognized by the Supreme Court, "close relatives and guardians, both of whom likely have intimate knowledge of a mentally retarded person's abilities and experiences, have valuable insights that should be considered during the involuntary commitment process." [Heller v. Doe, 509 U.S. 312, 329 (1993)].

Our love for our family members is what motivates our decisionmaking. When advocacy organizations, who have never even met our family members, work to undermine our legal decisionmaking authority, they are working toward an ideological end, whether or not in the best interest of our family members. Our fragile family members are mere pawns in their efforts to eliminate licensed facility care as one residential option for people with especially severe cognitive, physical and medical disabilities.

We respectfully request that the ABA Commission on Law and Aging and the ABA Commission on Mental and Physical Disability Law review our concerns and take action. We would welcome the opportunity to meet with you to further discuss this issue and explore ways that the ABA may help. Respected members of the legal community – from lawmakers, to attorneys, to judges – are in unique position to address this important issue.

Sincerely,

Sam Golden
Chair, VOR Government Affairs Committee

cc: Robin Sims, VOR President
VOR Board of Directors
VOR Government Affairs Committee